

Impact of cerebral palsy on the quality of life in patients and their families

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Abstract

Measuring QOL is a field that is gaining interest among researchers worldwide. This is a prospective, descriptive study that aimed to look at the impact of health-related quality of life (HRQL) of cerebral palsy in the lives of patients and their families. *Methods:* Patients attending the Paediatric Rehabilitation Clinic at University of Malaya Medical Centre were interviewed prospectively using the Lifestyle Assessment Questionnaire – Cerebral Palsy. *Results:* A total of 27 patients were interviewed. Three (11.1%) patients reported severely affected quality of life. Seven (25.9%) patients reported moderately affected quality of life and 10 (37%) reported mildly affected quality of life. The worst score of 76 were reported in 2 patients. The best score of 11 was reported in one patient.

Conclusion: The impairment and disability due to cerebral palsy is likely to be similar in both developing and developed countries. However, the quality and type of care received by patients are likely to determine the resultant handicap and the implication on the quality of life

INTRODUCTION

Cerebral palsy¹ is one of the most common chronic disabling condition of childhood.²⁻⁴ A prevalence of 1.2 to 2.5 per 1000 school age children has been quoted, but the rates vary from country to country and also within countries.²⁻⁶ Traditional research often focused on the reduction or relieve of disabilities associated with this condition. However disabilities affect significantly on the children's independence; and consequently on the lives of their caregivers. Traditional clinical researches are therefore not suitable to measure the impact of disability in cerebral palsy; which are better measured with other tools for example health status or quality of life (QOL).⁷⁻⁹

The measurement of QOL in children lags behind that of adults. In addition very few of these measurement are appropriate for children with developmental disabilities.¹⁰ Cerebral palsy can have a tremendous impact on the child's capacity to carry out activities of daily living (ADL); hence the impact on the QOL of the child and also his family. Various theoretical models of disability and chronic illness have been developed specifically for children with disabilities especially for children with cerebral palsy.^{7,9,11-12} The terminology 'health-related quality of life' (HRQL) refers to the health aspect of QOL, excluding issues like religious beliefs

and practices.¹³ The common challenge faced by researchers in the field of cerebral palsy is the inability of most children to communicate themselves thus, the need to rely on the caregiver for information regarding this aspect of health care.¹³

The measures developed aimed to capture the interaction between the child's condition, developmental stage and his social and cultural settings which give rise to disadvantages or handicaps, as classified under The International Classification of Impairments, Disabilities, and Handicaps (ICIDH).¹⁴ HRQL assessment tools are divided into 2 types, either generic or disease-specific. In this case, a disease-specific tool would be more appropriate in measuring the morbidity faced by the children and the impact of it on the family members.

METHODS

This is a prospective descriptive study of outpatients from the Paediatric Rehabilitation Clinic of University Malaya Medical Center diagnosed clinically to have cerebral palsy. Only patients whose ages ranged from 3 to 10 years old were included. Either one of the parents was interviewed anonymously using the Lifestyle Assessment Questionnaire-Cerebral Palsy (LAQ-CP), a disease-specific type of questionnaire that

was developed for the purpose of evaluating impact of disability in children with cerebral palsy.¹⁶ Mackie *et al* developed this questionnaire specifically for use in the North of England Collaborative Cerebral Palsy Survey in order to specifically capture the impact of impairment and disability on children with cerebral palsy and on their families.¹⁷ This questionnaire has been shown to be a reliable tool in measuring the disadvantages experienced by children with cerebral palsy in North England.⁷

The LAQ-CP is a 46-item questionnaire, organized into six dimensions through the application of multidimensional scaling.^{7,16} Dimensions are named to reflect elements of the ICDH classification with some modifications to reflect the experiences of the children and their families. The impact of the child's problems on the family emerges as an important issue. Some of the questions in the questionnaire were modified to suit local context. Each response to the items in the questionnaire was assigned a score from 0-4 using a scoring system as described in the LAQ-CP manual. Conversion of these raw scores into a final standard score, known as Lifestyle Assessment Score (LAS) is detailed in the manual. The LAS is expressed as a percentage score out of 100. A maximally disadvantaged child scores 100%. Using the descriptions of the score in the manual, an arbitrary classification of the quality of life according to the LAS Score was created as follows: Good (<30%); Mildly affected (30%-50%); Moderately affected (51%-70%); Severely affected (>70%).

Statistical analysis of data was done using Microsoft Excel. The *t*-test, the significance test and correlation/regression analysis were used for statistical calculations. *p* values <0.05 were considered statistically significant.

RESULTS

A total of 27 patients (13 males, 14 females) were interviewed. The Male : Female ratio is 1 : 1.08. The age ranged from 3 years 8 months old to 10 years 11 months old. The overall mean age is 7 years 4 months old. The mean age for males is 7 years 3 months old while for females is 7 years 5 months old. (Table I) The ethnic distribution is: Malays (44%), Indian (30%), Chinese (22%), others (4%).

The LAS for individual patient is illustrated in Figure 1. Using the arbitrary classification, 3 (11.1%) of them have severely affected QOL. Two patients had the highest score of 76. Majority had

mildly affected QOL (10 patients, 37%). There are 7 patients (25.9%) each in the categories of moderately affected QOL and good QOL. The lowest score was 11. The range between the highest and lowest score is 65.

For the overall group, the median score is 44 while the mean score is 44.89 with the standard deviation of 19.31. The median score, mean score and standard deviation for each gender group is illustrated in Table 2. *t*-test comparing between both gender group and also between each gender group and overall group were statistically insignificant.

Figure 2 shows the breakdown of LAS for each patient according to the respective domains. The LAS for each patient in this graph was less than the actual figure because the constant (4.05) was not included.

Age and LAS

A comparison was made to see if there was any correlation between age and LAS. (Figure 3, 4, 5) The correlation coefficient (*r*) for the overall group, female group and male group is 0.05, 0.08 and 0.01 respectively indicating very little correlation between the 3 groups. *t*-test were insignificant.

DISCUSSION

It has been reported that children with cerebral palsy and their carers have impaired health related QoL.^{19,21} The degree of impairment of QoL correlated with the severity of the condition.^{21,22} Although no data is available in Malaysia, it is believed that cerebral palsy is also one of the most common chronic disabling childhood conditions affecting the QoL. To the authors' knowledge, this is the first time a study was done to determine the QoL of life of patients with cerebral palsy in Malaysia.

Due to time constraints, the study was limited to descriptive nature. The dynamics of cerebral palsy and the various aspect of QoL were not analysed in detail, hence a direct comparison with other studies could not be done. Four areas of health related QoL were identified in the study by Young *et al*, namely social relationships; home and school environment; self and body; recreational activities and resources.²⁰ In addition to these domains, children also reported other areas which were not included in the generic QoL inventory, namely relationships with family members other than parents; inclusion and fairness; home life and neighborhood; pain and discomfort;

Table 1: Patient's background data and Lifestyle Assessment Score (LAS)

No	Age	Sex	LAS
1	3 years 8 months	F	63
2	3 years 9 months	F	48
3	4 years 10 months	F	28
4	5 years 1 month	F	31
5	5 years 3 months	F	11
6	5 years 3 months	F	44
7	5 years 6 months	F	76
8	9 years 1 month	F	39
9	9 years 7 months	F	57
10	9 years 10 months	F	46
11	10 years 0 months	F	44
12	10 years 2 months	F	67
13	10 years 7 months	F	18
14	10 years 11 months	F	27
15	3 years10 months	M	43
16	4 years 4 months	M	36
17	5 years 5 months	M	64
18	5 years 6 months	M	50
19	6 years 3 months	M	66
20	6 years 7 months	M	23
21	6 years 8 months	M	24
22	7 years 1 month	M	56
23	8 years 11 months	M	76
24	9 years 3 months	M	73
25	9 years 9 months	M	57
26	10 years 4 months	M	32
27	10 years 5 months	M	13

environmental accommodation of needs; and resources other than finances and time.

These studies have crucial and important implications on QoL by Malaysia children with cerebral palsy. This is due to the significantly

different quality of provision and support between a developing country, e.g. Malaysia and a developed country e.g. United Kingdom (UK) for children with chronic disability. In UK, the government provides healthcare to 90% of

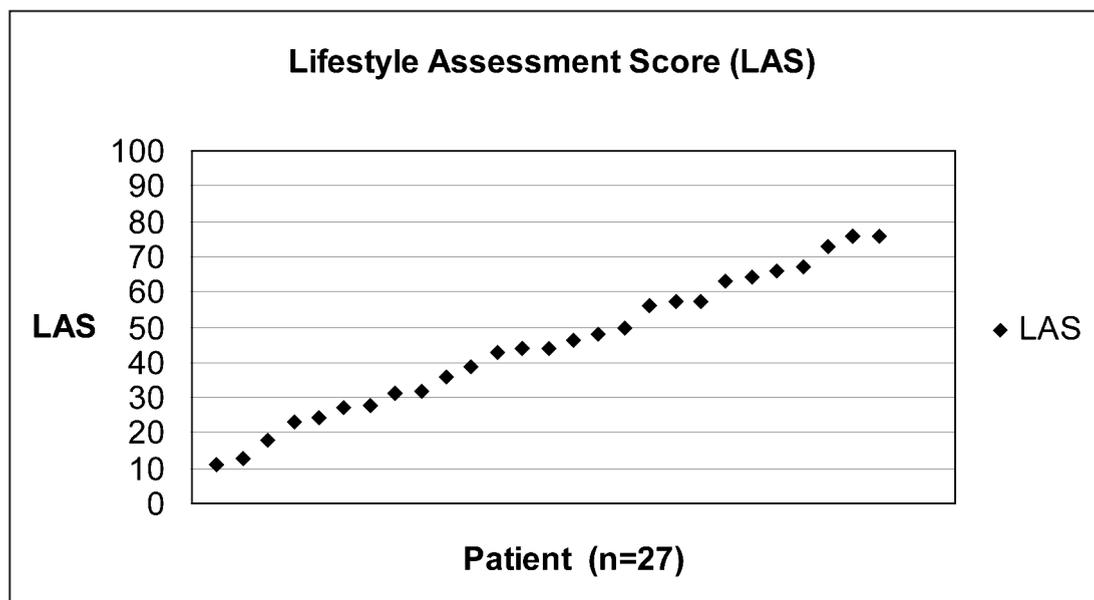


Figure 1: Lifestyle Assessment Score (LAS) for each individual patient

the paediatric population. An array of services like health visitor, home help, social worker, community nurse and voluntary services are available to assist the parents or caregivers of children with cerebral palsy. In addition various non-governmental organizations are set up to provide local support to these children and their families. For example, Scope, a non governmental organization in England and Wales focuses on people with cerebral palsy.¹⁸ The services provided include assistance in daily living, education and work, just to name a few. Professional respite care is also available for the carers to allow them to take a break from the daily chores of taking care

of the children.

In Malaysia, there is lack of these services for patients with disability, e.g. cerebral palsy or to their parents or carers. This is probably due to lack of awareness and complicated by limited resources. Limited resources e.g. money and skilled manpower are the main problems faced by our government in providing satisfactory healthcare to these people. Consequently, the response has always been managing the disabilities and complication as they arise rather than minimizing or preventing disability. In addition these services provided are confined mainly to tertiary and major general hospitals and

Table 2: Lifestyle Assessment Score (LAS) classification for overall, male and female group

LAS	Male (n=13)	Female (n=14)	Overall (n=27)
< 30	3	4	7
30 – 50	4	6	10
50 – 70	4	3	7
> 70	2	1	3
Mean score	47.15	42.79	44.89
Std. Dev.	20.37	18.78	19.31
Median score	50	44	44

Groups compared: Males and Females (t -test value 0.5786); Males and overall (t -test value 0.3406); Females and overall (t -test value 0.3334), all p -value>0.05

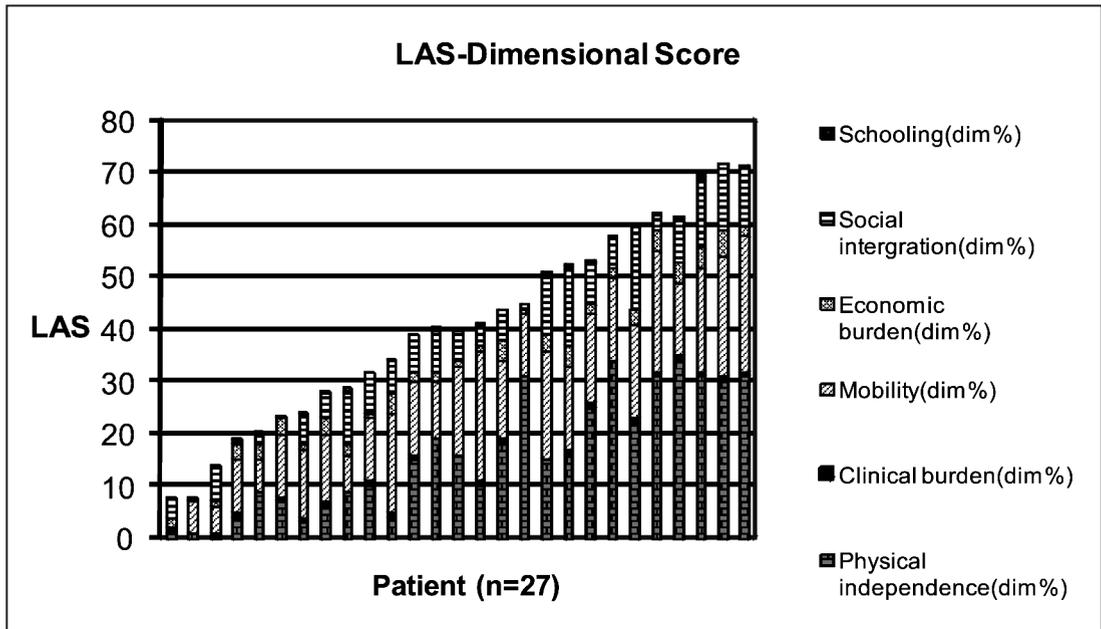


Figure 2: Dimensional breakdown of LAS for each individual patient

are not readily accessible to all who require it. The extended family system in Malaysia is crucial in filling these service vacuums. In this study, 5 out of 27 of the families had crucial support for help if the need arises. Lack of awareness and apathy

among the public are also contributing factors in why disabled children received little support from the public.

The financial burden borne by the families of patients is also not adequately addressed locally.

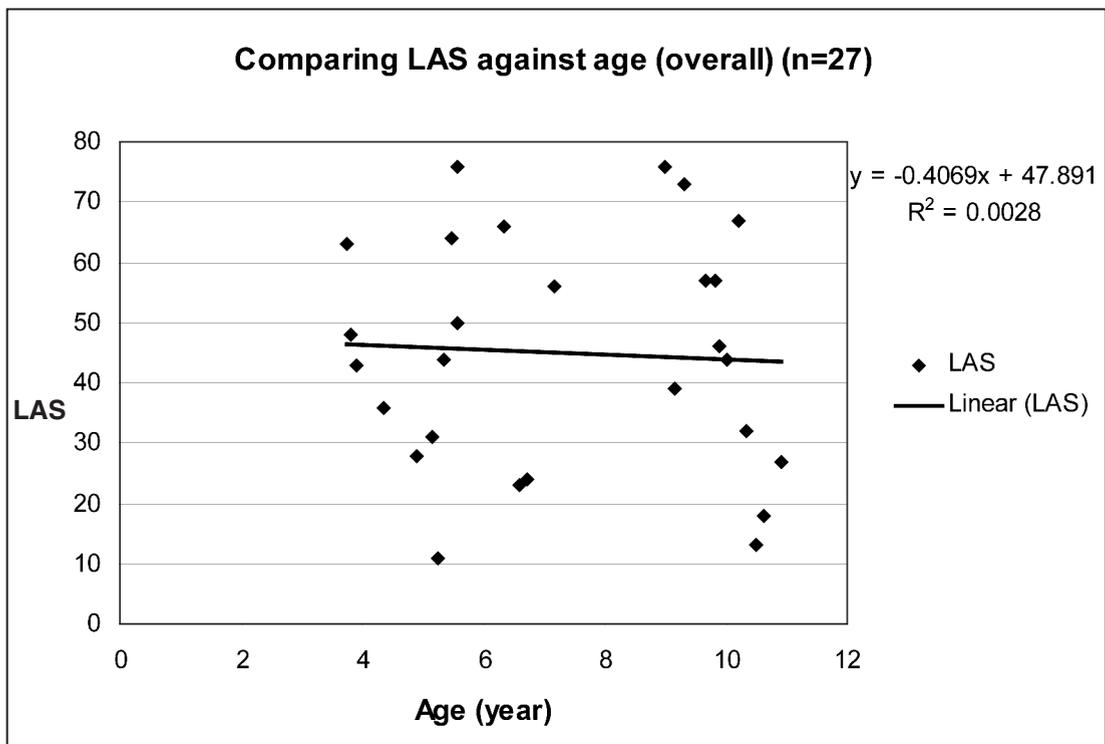


Figure 3: LAS and age for overall group

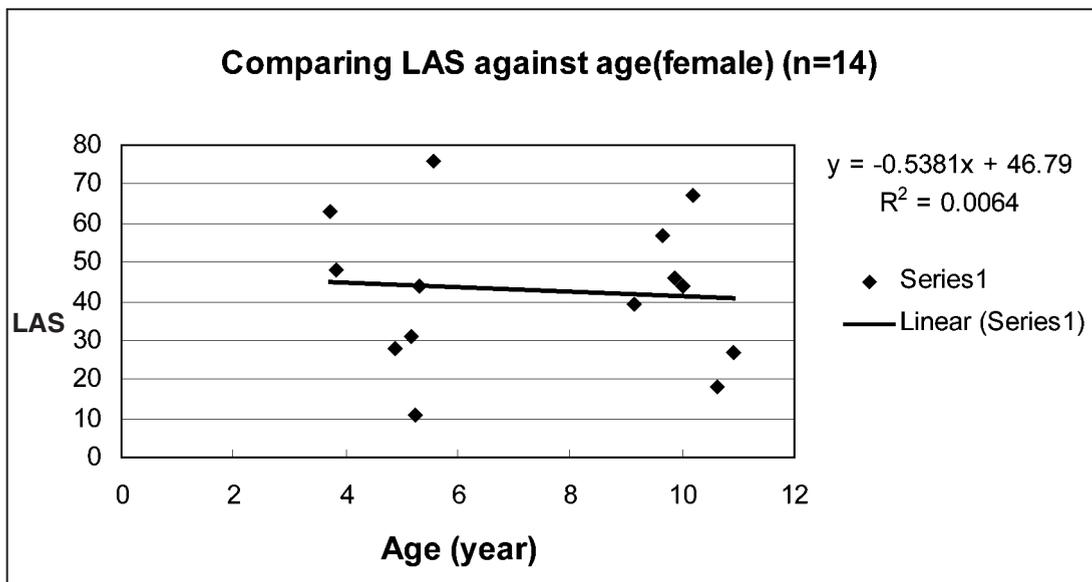


Figure 4: LAS and age for female group

The Welfare Department subsidizes certain orthoptic equipments and supports like standing frame, orthoses and wheelchair *etc*, which may be necessary in helping them attain functional use of their limbs and bodies. However, there are other needs which are not addressed. For example, travel expenditure for hospital, rehabilitation and clinic attendances, modification of the house to allow greater mobility and also access to crucial amenities. In UK, child with cerebral palsy and other disabilities receive various disability related allowances to lessen the financial burden.¹⁸

In conclusion, the LAQ-CP questionnaire used in this study has proved to be useful in recording the quality of life in patients with cerebral palsy in Malaysia. This study has highlighted several differences in the management of cerebral palsy between Malaysia, a developing nation and United Kingdom, a developed nation. Time constraint has limited this to a descriptive study. With adequate sample, further study can be done to look at the dynamics of this condition and their influence in the QoL, for example, the relationship between the type of cerebral palsy and QoL.

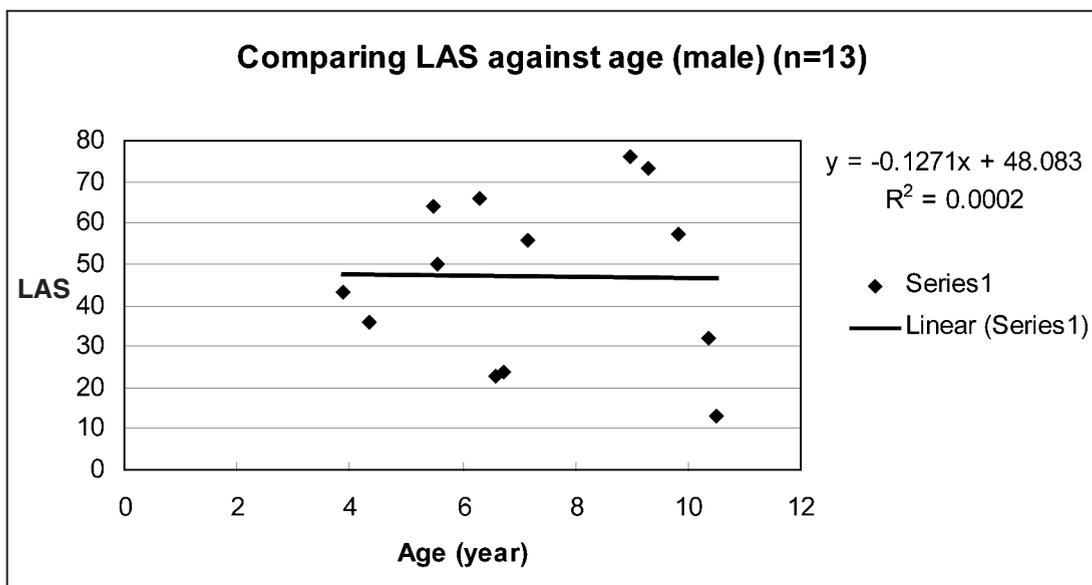


Figure 5: LAS and age for male group

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